

REALTIME TEXT FILE

DISABILITY AND HEALTH PROGRAM
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>> MEAGAN SULLIVAN: All right. It's 10:00 o'clock, so let's go ahead and get started. Good morning, everyone. This is Meagan Sullivan with the Florida Disability and Health Program. Thank you for joining us for our fourth quarter Disability Community Planning Group call. We are happy to have Tyler James on our call today. Tyler G. James is a Certified Health Education Specialist and doctoral student in the Department of Health Education and Behavior at the University of Florida. His talk, "Identifying Deaf Health Disparities in Florida" discusses the community stakeholder engagement process and how a needs assessment survey was translated into American Sign Language to measure health disparities and health information needs of the Florida Deaf community. Everyone is on mute and as questions come up, please type them in the chat box and we will read them out loud after Tyler is finished. Thank you for joining us. And you should be able to see Tyler's presentation and our interpreter, David Phillips, on the screen. You may need to move your control panel to see him. I will pass it over to Tyler. Go ahead.

>> TYLER JAMES: This is Tyler speaking. Thank you, Meagan, for that introduction and thank you to all of the attendees who are watching.

As Meagan mentioned today, I will be discussing an ongoing research study on identifying Deaf health disparities among the Florida Deaf population. Just for a general note, as we progress through the slides, I will be providing about a three second lag before I start presenting to allow all attendees to read over the slide before I start providing the verbal content.

So, before we get started, I wanted to briefly describe the group of people that we have working on this project. For reasons that will become clear later in this presentation, I want to especially thank Mr. Stephen Hardy, Dr. Glenna Ashton, and Ms. Zulma Sewell, for the work they have dedicated to the project. In addition, I would like to thank Dr. Mike McKee for his guidance and support since this project's conception, and my

supervisor, Dr. JeeWon Cheong for helping me troubleshoot as unexpected things had occurred.

[Pause].

>> TYLER JAMES: Today's presentation will be broken down into four parts. I want to provide a brief introduction to the field of Deaf health disparities, then discuss the community engagement process for the current project, how we design and translated our survey, and then finish with future directions for the project. So for some background knowledge.

[Pause].

>> TYLER JAMES: When thinking about Deaf health disparities, it's important to consider that there is the larger population of deaf individuals indicated by the lower case d and then there is a subpopulation of capital D Deaf individuals. The lower case d deaf indicates a medical diagnosis of deafness or hearing loss. This is used to describe people with profound deafness and people who are hard of hearing. They may use a variety of communication modalities including sign language and spoken English and they generally do not ascribe to Deaf culture.

The capital D Deaf community consists of people who are clinically deaf but also members of a community with a shared culture including language; in the United States it's typically American Sign Language, history and literature.

For the purpose of this presentation, I will be focused on the capital D Deaf community also known as culturally Deaf American Sign Language users. As a general note, on person-first language English, the capital D Deaf is used as a noun by the community; thus instead of saying a person who is deaf, we would say a Deaf person.

Important to the field of Deaf health is the language used by the U.S. Deaf population, which is American Sign Language. ASL is a manual language primarily used by Deaf and hard-of-hearing individuals to communicate. It's important to recognize that ASL is a formal language, it's not a gesture system or a system of English words on our hands. ASL has a very well researched grammatical structure and vocabulary just like other spoken and signed languages. And because of the use of a language that is not English, this population is typically deemed limited English proficient, or LEP. They have been recognized as having an average English literacy level of that of a fifth or sixth grader. Unfortunately due to poor data collection, we do not have estimates of the size of this population. However, the literature indicates that this population may be anywhere from 100,000 to one million unique individuals.

[Pause].

>> TYLER JAMES: Dr. Stephen Barnett, the director of the Rochester Prevention Center, National Center for Deaf Health Research and colleagues published these words in 2011: The lack of the most rudimentary health statistics from deaf populations thwarts efforts to engage Deaf communities in setting priorities for health improvement and chronic disease prevention programs. Still today we face a barrier of having limited data on this population.

[Pause].

>> TYLER JAMES: When we think of governmental data sources, we have to recognize the limitations and lack of representation of Deaf ASL users in collection of those data. For example, the United States census, which is responsible for counting the number of individuals in the country does not count the number of individuals who use ASL. In fact, they specifically state that they count ASL speakers among those who speak English. This is a direct quote that I pulled from their website earlier this month: The three questions used to capture languages spoken and English-speaking ability are not designed to identify American Sign Language users. The Census Bureau counts ASL speakers among those who speak English. And so whatever is a population that might have limited English speaking proficiency, this would be the most accurate way to count those individuals.
[Pause].

>> TYLER JAMES: In addition, we lack health information on this population. As you know, the Centers for Disease Control and Prevention are responsible for assessing and improving the nation's health. To understand where we need to improve, we have to know where we are and CDC assesses the nation's health using a variety of surveys and the most popular is called the BRFSS or the behavioral risk factor surveillance system. The BRFSS is a telephone survey that asks residents about their health behaviors, chronic disease conditions like diabetes and heart disease, and their use of preventative services.

Every year, CDC interviews over 400,000 people in the country. However, the national and state BRFSS did not include a question regarding Deaf or hard of hearing until 2016. Even then, BRFSS is a random dialing system and this is conducted using a telephone, which Deaf people do not use the same way hearing people do. So typically Deaf ASL users communicate on the telephone using the video relay service, also known as VRS. This is a federally-funded service that allows Deaf and hard-of-hearing ASL users to have access the telephone conversations with spoken language speakers through the use of an interpreter. The Deaf or hard-of-hearing individual can call a hearing person through the video system, be connected to an interpreter, who will interpret the conversation back and forth and with the hearing consumer as well.

When we think about using the video relay service for surveys, we have two major concerns. The first is that we do not have access of the full database of VRS numbers which would allow us to call Deaf and hard-of-hearing ASL users. Having this type of database, of course, would cause a privacy concern for those customers. The second issue is that interpreters can be located anywhere across the country and may not have intimate knowledge on the regional dialects being using or the survey we are using. This can decrease the accuracy of the interpretation of the survey items, as different interpreters may sign in different ways and ultimately that may impact the results.
[Pause].

>> TYLER JAMES: In 2004, the Centers for Disease Control provided funding to the University of Rochester to create a CDC prevention research center now known as the National Center for Deaf Health Research. This was seen as probably the answer to the problem for the lack of representation for Deaf individuals and medical research. The prevention research centers were meant to focus on a specific health problem

unique to a geographic location. Rochester, New York, is particularly unique because it has one of the largest reported per capita Deaf populations in the United States. This is attributed to the large number of Deaf services available for healthcare access and access to higher education, with the National Technical Institute of the Deaf being located at Rochester Institute of Technology.

The University of Rochester partnered with the local Deaf community to begin to address the health and equity experience by the community. In this process, they translated the CDC's behavioral risk factors surveillance system into American Sign Language and started the Rochester Deaf health surveys to measure Deaf health disparities.

[Pause].

>> TYLER JAMES: Through their community partnership, we have started to identify several health disparities among Deaf ASL users. For example, Deaf ASL users are seven times more likely to have inadequate health literacy than their hearing-speaking peers. In addition, Deaf ASL users are more likely to use the emergency room in the past three years. Some other health disparities include higher rates of mental health diagnoses, higher victimization of interpersonal violence, higher cardiovascular risk, more marijuana use, and more sexual partners.

However, a significant limitation to this research that we currently have is the potential of lack of representativeness of the Rochester Deaf community to other Deaf communities across the country. In some studies from the Rochester Deaf community, over 50% of participants have a four-year degree or higher, which is likely not indicative of the U.S. Deaf population and, thus, it's possible that the health disparities are more severe than we've already identified.

[Pause].

>> TYLER JAMES: I do want to point out that there are some Deaf health researchers who are Deaf themselves working to solve the issue of representative samples. Dr. McKee and Zazove at the University of Michigan have been collecting data in Michigan for quite some time. Dr. Kushalnagar at Gallaudet University in D.C. has led an effort of translating surveys of the Health Information National Trend Survey in collecting data throughout the country.

But still, to our knowledge, the Florida Deaf community has not been the population of interest for health needs assessments and this is important because we are the third largest state in the U.S. by population. And Florida also does not have the strongest Deaf services or policies and so it's possible the health of Deaf Floridians has been negatively impacted by this.

[Pause].

>> TYLER JAMES: So the current study received preliminary approval from the University of Florida Institutional Review Board which is an ethics board meant to protect human research participants. Our Florida Deaf Community Health Needs Assessment hopes to use social media, community service centers, and community members to help people using ASL and ASL-using Floridians.

[Pause].

>> TYLER JAMES: So now I'll get a little bit into how to engage the community for this project. As most of you are probably aware, historically, communities have known researchers to be a group who conducts research on them as opposed to with them, and this can lead to researchers being mistrusted by communities, communities feeling used, and also hurt communities after research resources are taken away.

The Deaf community, the prime example of a community who has experienced this. During the late 1800's to the mid-1900's, the eugenic movement was prevalent throughout the United States and Western Europe. During the movement, researchers started discussing sterilization of Deaf individuals to "reduce social burden." Another prominent example of this movement is the oralism movement promoted by Alexander Graham Bell and as this movement focused on the Deaf person as a disabled person who needed to be taught speech and have their hearing abilities amplified and so these movements are still seen today. Deaf communities are predominantly seen as disabled communities who are not permitted to engage with researchers who focus on Deaf medical research.

And so accordingly, Deaf individuals have become more and more mistrusting of medical researchers for fear of having genetic engineering that could destroy the community. So going into this research project, we knew that we needed to engage the Deaf community early and often.
[Pause].

>> TYLER JAMES: There are several established practices regarding research that engages communities and typically this research falls under the realm of community-based participatory research also known as CBPR. CBPR is a framework and an approach of research where community members and researchers are both respected as experts. Community-based participatory research is typically led or co-led by leaders who are trying to accomplish community action. Importantly, the philosophy of CBPR research is to be mutually beneficial, if not more beneficial to the community. The main purpose of this strategy is to build community capacity and so researchers have an opportunity to test novel interventions and disseminate scientific work, while communities have the opportunity to create sustainable programs and advocate for more resources to be allocated in their communities.
[Pause].

>> TYLER JAMES: And so there are some downsides to the CBPR. Notably, it can be very expensive. For example, the CBPRs at the National Center for Deaf Research are funded by grants by CDC and the National Institutes of Health. Research here in the Florida Deaf Health Needs Assessment is not funded. Last May, we did apply for a grant to a professional organization called The Society for Public Health Education, but we were unsuccessful at getting funded. And so because of the limited resources, we found we would have a limited capacity to do a pure community-based participatory research approach for the entire state of Florida.
[Pause].

>> TYLER JAMES: Because of our limited resources, we chose a community engaged research approach for this project. Community engaged research continues to emphasize a collaboration between the community and researchers but a major

difference is that community engaged research is typically research initiated with feedback from the community. A particular strength of community engaged research is the recognition that community members have different strengths that can be incorporated at each step of the research process. Community members can provide feedback on research question development, research can become more translatable, help with gaining community support and with participant recruitment, and improve the measurement tools being used.

Overall, we recognize that using a community engaged research approach would give us similar benefits to CBPR, while also keeping costs low.
[Pause].

>> TYLER JAMES: To start the community engagement process, we decided to create a Deaf Community Advisory Work Group. This work group would be approximately 3-6 people who are culturally Deaf ASL users that could provide unique cultural insight into our research. Prior to inviting potential members to the work group, we wanted to ensure that they met several criteria.

The first was diversity; we wanted our work group members to be diverse in experience, geographic location, and demographics. Of course it would be easier for me to find Deaf individuals here in the local Gainesville community, which is where I'm based out of, but that wouldn't have reached the entire state of Florida. Diversity was important for us for two main reasons. The first is when community members provided feedback on surveys and results, we wanted them to be able to use their backgrounds to give their honest feedback. Having a diverse experience provides more useable feedback.

The second reason we prioritized diversity is the pivotal role that people would play in recruiting participants. For example, if we had a group of young Deaf adults from the Gainesville area, we might only get respondents who were young from the North Central area. It was important for us that they had a social network of Deaf community members that they would feel comfortable contacting about the survey.

The last criteria was to have an affiliation with the Deaf community organization in Florida that could be approached to assist us in our recruitment and our efforts.
[Pause].

>> TYLER JAMES: Currently our Community Advisory Work Group for this project has three members on it, all from different geographic locations in Florida. Dr. Glenna Ashton who is pictured on the left side of the screen is from South Florida. She recently -- oops, I apologize; there we go -- she recently ended her term as the secretary for the Florida Association of the Deaf and she is currently the Chair of the Florida Coordinating Council for the Deaf and Hard of Hearing which is funded by the Legislature through the Department of Health who addresses Deaf, hard of hearing, and deaf-blind health concerns. She also happens to be one of my former ASL teachers. Mr. Stephen Hardy is a current faculty member in the Department of Speech Language and Sciences at the University of Florida where he teaches American Sign Language and Deaf Studies. He is the former president of the Florida Association of the Deaf and former president of the Florida Association of the Deaf and the Gainesville Deaf Club.

The third member of our Community Advisory Work Group is pictured on the far right, Ms. Zulma Sewell. A Puerto Rican native, Ms. Sewell is in the Tampa/Clearwater area and works as an ASL instructor for the University of South Florida and St. Petersburg Community College. She's also heavily involved in the Deaf Literacy Center in Pinellas County, which is a strong community-based organization collaborated through the Pinellas County Public Library System.

[Pause].

>> TYLER JAMES: Our Community Advisory Work Group members participate in a range of responsibilities as their schedule allows. And the work group was primarily responsible for working with the research team in developing the survey construct domain and helping translate questions, a topic that we'll be discussing in depth shortly. The members were also pivotal in getting introductions to community organization leaders so that we could get community buy-in on the project. And in the future, the work group members will help recruiting survey participants. And after the survey is complete, will help interpreting the results.

Again, this is using a community engaged research philosophy as opposed to CBPR. For example, the National Center for Deaf Health Research has a translation work group made up of members, researchers, and sign language interpreters who oversee that process. With our limited resources, we're trying to make this project as community oriented as possible, while also recognizing that the community work group members are providing support without monetary compensation.

[Pause].

>> TYLER JAMES: So I also want to provide a little bit about the logistics of how the work group is meeting. So I have so far led meetings through e-mails and video conferencing software and I have been meeting regularly with the work group members individually outside of those e-mails and video conferencing to discuss the survey development process and getting their direct insight. And we primarily meet using video phone.

And I also have regular meetings with the advisory group chairperson, Mr. Stephen Hardy. In addition, we're getting ready to schedule a first either face-to-face or video conferencing meeting to discuss the survey recruitment process as we're getting ready to launch the survey.

But of importance with both CBPR and community engaged research is that community members should also be provided the opportunity to be co-authors on research outputs like publications and presentations, which is something that we built directly into our framework. In fact, last month at the Society for Public Health Education, we presented a poster very similar to this current presentation where all work group members collaborated on creating that poster and were listed as authors accordingly.

[Pause].

>> TYLER JAMES: So as some of you may remember, in the June 2017 webinar, Dr. Tony Delisle, the executive director of the Center for Independent Living in North Central Florida, spoke on the importance of engaging community-based organizations and addressing the challenges associated with research involving communities that are spread out over large geographic regions and he also discussed how we should be

earning the trust of community members. So, of course, we wanted to get buy-in from large Deaf community organizations who could help us facilitate buy-ins, assist with recruitment efforts, and help disseminate findings. But, of course, we had this looming question of which community organization should we partner with?
[Pause].

>> TYLER JAMES: And prior to answering that question, we had to answer the question of where are Deaf Floridians, which is a more difficult question to answer, in my opinion. The lack of governmental data collection really reduces our ability to find geographic areas of high Deaf ASL-user concentration. However, based on our team's knowledge and members in the community, we assume that Tampa, Jacksonville, Orlando, and the Miami area communities are the largest in the state. Of course, this was just based on community reports which could be a research study in and of itself.
[Pause].

>> TYLER JAMES: So to answer the question of where are Deaf Floridians, we turn to vocational rehabilitation, also known as voc rehab or VR. VR is a federal and state funded program for people with disabilities to gain job training, employment accommodations, and receive job-seeking skill coaching so they can get and keep a job.

The National Center on Post-Secondary Outcomes and the Florida Coordinating Council for the Deaf and Hard of Hearing estimates that only 45% of Deaf and hard-of-hearing Floridians are employed. That means that 55% of the population is not employed. So if a person is Deaf and unemployed and seeking a job, they may not be using the services of vocational rehabilitation. Thankfully, VR does collect data on their customers, so we requested that data to see where the Deaf and hard-of-hearing Floridians were.
[Pause].

>> TYLER JAMES: And so we requested VR to provide us with the county level numbers of unique Deaf and hard-of-hearing customers who had an active VR case between January 1, 2012 and June 27, 2017.

After receiving the data from VR, we used geographic information system, or GIS technology, to map the Deaf and hard-of-hearing population in Florida. And as you can see on the map, darker red areas are areas of higher deaf concentration within the VR customer database and the areas in the lighter yellow are of lower concentration. And this confirmed our initial assumptions that the larger communities included the Miami area, Tampa and Clearwater areas, Orlando, and Jacksonville. This map does not represent the total number of Deaf and hard-of-hearing ASL-using Floridians. Unfortunately, we are unable to receive the number of Deaf ASL users who use VR. And in addition, not all Deaf and hard-of-hearing individuals use VR services.
[Pause].

>> TYLER JAMES: So using our map would help concentrate our efforts on service centers with strong ties to larger communities. The knowledge of the Deaf Community Advisory Work Group, tied with the research team's knowledge of the community, and the internet helped us to create a list of Deaf community-based organizations throughout the state.

In addition to using the Florida Department of State's registries of listed non-profit businesses, we also used Facebook, which is very highly used by the Deaf community. We searched both group pages as well as Facebook like pages for businesses and organizations to determine where some of the larger community organizations were. And some of the examples that we got from this entire search included the Florida Association of the Deaf, the Deaf Literacy Center in Safety Harbor, Florida, which is near Clearwater, and the Tri-County Association of the Deaf.
[Pause].

>> TYLER JAMES: And so after collecting the information about Deaf and disability-related organizations in Florida, we returned to our VR map and plotted the location of those centers. I apologize for the size of the map; I'm actually going to make it bigger right now. Okay. So if you're looking at the map, you'll see that we plotted both Deaf Service Centers and Disability Service Centers, which includes Deaf community-based organizations.

The blue boxes with the stars are the Deaf Service Centers or community organizations; the Disability Service Centers are the ones with the green wheelchair international accessibility icon. And so, for example, the Disability Service Centers include things like Centers for Independent Living or Multi-Disability Service Centers. While the blue stars represent things like up here in St. Augustine, we have the Florida School for the Deaf Alumni Association. We also have the Safety Harbor/Pinellas County Public Library which includes the Deaf Literacy Center, and as well as things over in Escambia like Deaf and Hard-of-Hearing Services of the Emerald Coast.
[Pause].

>> TYLER JAMES: So this map really helps us to be able to recognize where we should be concentrating our efforts for recruitment and also told us which community partnerships we should be trying to prioritize.

So, for instance, the Tampa Clearwater area has about four Deaf Services and organizations, as well as Multi-Disability Service Centers that can be partnered to help disseminate that survey.

And so now I'd like to start talking about the survey's translation and dissemination process, in addition to how we developed it. So, going back to that first figure that I showed back in the background section on Deaf health disparities, we had this long list of Deaf health disparities that could easily be measured on our survey.

For instance, out of my own interest, I'm very interested in health literacy in addition to emergency room use and HIV testing behaviors. But that wouldn't provide us with the necessary community insight that we wanted to make this project more community engaged.

And so whenever we consider creating a survey, I think it's important to consider the philosophical grounding of that survey development process. In the field of health research, we have two major constructs, the community's perceived needs and the community's "actual needs." Community perceived needs are issues and priorities that the community feels needs to be addressed to better help and quality of life. Similarly,

the actual disparities are researchers have diagnosed as issues that need to be resolved to help the quality of life. And at times, these may overlap, but quite often you'll see that community priorities are not addressed.

When we consider research in programs that will address the community perceived and actual needs, we also need to think about the resources and fundings that are available to do that research and the policies that may make that research more useable. If there are not resources or funding, then the researcher program is generally not developed or implemented. But when all three of these constructs overlap, we find action that is important for communities, researchers, and policymakers.

The research that I do is try to make these areas overlap as large as possible. To do this, we have several techniques we can employ. Techniques in the field of health education try to make researchers recognize that the community's perceived needs are actual needs. Similarly, participatory research strategies including community engaged research where we're bringing community members to the table with researchers can help the community members recognize the actual needs and also be the community's perceived needs.

In addition, we can use community mobilization methods and organizational development so that we can try to push those resources higher so that they overlap more with the perceived and actual needs. In addition, we can use health services research which is typically researcher initiated funded by, like, NIH or CDC, so there is typically some overlap between researches and actual needs and pull those closer by using health services research.

But if we want to increase resources to address community perceived needs, then we need to use advocacy techniques. So when developing our survey, we kept this strategic plan in mind. We wanted our research to extend the current knowledge on Deaf health disparities, while addressing the needs of the Florida Deaf community. And of major importance, we wanted our research to be useable for advocacy strategies to support future resource allocation. And like I said, we want all of these circles to overlap so that action area is as large as possible.
[Pause].

>> TYLER JAMES: So now I'm going to discuss our first draft of the survey that we had come up with based off of the domain that came about based on research perceived need, as well as community need.

The first is health literacy. So this is a very big issue in the Deaf community because for the Deaf individuals, despite having average IQs, if not higher than average IQs, there is a fund of information deficit due to being systematically barred from accessing information that isn't made accessible to them. And so the community has a big concern about Deaf community members not knowing healthy foods to eat, how to manage their diabetes, how to prevent health conditions from occurring, which all falls under the realm of health literacy and we marked that for community needs, in addition to actual needs that researchers have found.

And then in addition, so whenever I was working as a practitioner in health education,

something I was always very interested in was the greatest health concern. What does an individual believe the greatest health concern to them is and trying to map that onto a community. And one of the things we're going to be asking Deaf community members to select from a list of health domains to determine which domain is of more importance to them.

Mental health is also a large community need, so both the Florida Association of the Deaf and the National Association of the Deaf have defined mental health as major priorities. And it is also -- we found research from the Rochester sample that the Deaf community does have more mental health diagnoses and more negative mental health access conditions than the hearing population and so this was also an actual need. So on our survey, we are using a scale called the PHQ2 and that is a depression screening measure that will basically show if a person is at high risk or low risk for depression.

In addition, we were very interested in healthcare access, both at the community need and at the actual needs level. But we're measuring it very broadly. So not only are we looking at primary care access in emergency department use, but the Florida Association of the Deaf was very interested if people have access to an interpreter. Over the past three years, there have been several lawsuits, especially in South Florida, regarding hospitals not providing interpreter services. And if they are, then they may not be providing qualified services. And we're asking if they were denied an interpreter they requested in a medical facility in the last 12 months.

Other items related to healthcare access, such as the emergency department and primary care items were adapted from the behavioral risk factor surveillance system. And then the last one was healthcare communication -- oh, excuse me -- health behaviors, which includes tobacco use, HIV testing, binge drinking, and sunburn, a variety of items that have implications for the health of the Deaf community, including future cancer diagnoses, cardiovascular disease prevention.

And then the very last one is healthcare communication; so did they feel like their doctors were spending enough time explaining things to them, respecting their health concerns, and respecting their decisions.

However, what we saw with that, there was a large proportion in our survey that were actual need and not enough of the community need. In addition, there was just a large number of items in general, which is bad because this was a pilot survey, and so we wanted to make sure that we emphasized community need, while also getting the number of items down.

And so what we decided to do was to delete the healthcare communication items, as well as the behavior intent items, and so this is -- in total, we have 37 items and these are the constructs we were measuring.

And so there's a more equal distribution. Whenever we actually look at the individual survey questions, there's actually more of a community need in what they are than the actual need.

And so of course we translated this into American Sign Language, which is the process I would like to start now. After we created the draft of the English survey and we have

Community Advisory Work Group feedback from that survey, I then gave that survey to a Deaf interpreter. A Deaf interpreter is a person who is Deaf themselves that linguistically specializes in communicating in sign language for a variety of stakeholders. So since we wouldn't be able to tailor this survey to a person's specific signing needs, we wanted it to be accessible to as large a number of individuals as possible.

And so after providing that survey, the English written survey to the Deaf interpreter and he translated it into American Sign Language, and then I reviewed it. I wanted to review it first just because I wanted to make sure that the questions were being translated into the appropriate construct that I was needing them to.

For example, in HIV testing, I could just ask a hearing English speaker oh, have you ever gotten a HIV test? But in the Deaf community, we should be describing that such as the oral swab, blood draw, or doing a finger prick test, and so all of this has to be incorporated into the translation in order for all of these items to be valid.

After I provided the feedback to him, he then created a second draft of some of the items and some of the items of the first draft moved forward, and we sent them to the translation review team of the Deaf Advisory Work Group and they all reviewed the items.

And we provided them a rubric based off of three constructs. The first was if there was representation of the English construct in signs and that was a yes or no. The second was if they believed in their opinion that the signs were accessible to a large number of deaf individuals. And if either of those two items were answered no, then they were asked to please provide an adequate translation that would match what they perceived the item to need.

After that feedback was received, we sent it back to the Deaf interpreter for a third draft translation, which we then sent to a blind back translation interpreter. And actually the interpreter on the screen is working on this project and so he's very intimate with the project's knowledge.

So we did not provide the interpreter who is doing the blind back translation with the English survey, we only provided them the ASL interpretations. And so they then translated it back to written English, I then matched them up into an Excel spreadsheet and determined which ones matched up perfectly and those that did not. And those that did not match perfectly, I met with the interpreters and discussed if the items were sufficiently translated or if they needed to be retranslated.

And then we did our final translations in a studio here at the University of Florida in the College for Health and Human Performance, where we are now getting ready to notify the IRB that the translations were deemed as valid by the interpreting team so that we can continue the project.

[Pause].

>> TYLER JAMES: I do have a few survey challenges that I wanted to discuss. The first is Hurricane Irma, and so as many of you remember, Irma made landfall in Florida on September 10, which was right in the middle of us getting ready to do our round of Deaf Community Advisory Work Group reviews for translations and so, of course, power and flooding -- there was power outages throughout the state in addition to flooding

throughout the state.

And we wanted to be respectful of the group. Some of them had water leaks in their house, there was one interpreter working on the translation who was from Sarasota which did not receive adequate access to prepare for the storm and so cleanup was kind of hard.

So we wanted to be respectful to the Deaf community and not rush through the translation because it was important the translation be spot on. And so whenever we were thinking about our timetable, we initially allocated about two months for the translation process and it took us actually about three and a half months because of Irma and the cleanup that had to happen after Irma.

There are additional challenges related to the differences in language between English and ASL. Notably, some English concepts do not translate into ASL, like some German words do not translate into English, and so this is very common across languages.

But whenever we are considering how we can ask health-related questions without overloading a person's cognitive -- making them cognitively taxed, excuse me, it's important to think about how we can more accurately translate it.

And one is a -- one concept is an alcoholic drink and sign language. If you'll look at the interpreter, we'll sign a few different words so you can just see they are different signs. The first is like a normal drink like you would be drinking is glass of water. The other is like a mug of beer. A glass of wine. Or a shot of liquor.

And so if I'm trying to ask the question related to binge drinking, which is having five drinks if you're a man in a two-hour period or having four drinks if you're a woman in a two-hour period, I don't want to have to make my translators work through every single concept of a drink.

In addition, I don't want to have to provide the Deaf participant all of that information and potentially make them cognitively taxed.

And so to make it easier to understand, we use pictorial representations which are shown on the screen. So we have a can of beer, a beer mug, a glass of wine, as well as other glasses of mixed liquors, and a shot. And so what we were able to do through the Deaf interpreter, he is indexing to identify that all of those things are considered a drink before asking the question related to how many drinks have you had in the past 30 days.

[Pause].

>> TYLER JAMES: In addition, I want to discuss our informed consent translation process. So for those of you not familiar with research methods, informed consent provides information so that people can voluntarily participate in the research. We are required by the Federal Government to ensure that people understand the purpose of the study, all of the risks that we perceive to be involved, in addition to the potential benefits, and how we as researchers are going to minimize the risk of those negative consequences happening.

And so all of this is provided so that a person can willingly and voluntarily decide if they want to participate in a research study or not. These are typically written in English, which if we're dealing with a limited English proficient population, we should not be providing them information in English, we need to be providing it in the language that they know.

So based off of research that occurred at the National Center for Deaf Health Research, we have created a video dialogue of an informed consent. So here we have Stephen Hardy with our Deaf interpreter. The Deaf interpreter is acting as a member of the research team and Mr. Hardy is acting as a member of the Deaf community potential participant. And Mr. Hardy is asking to participate in the survey. So we're covering about eligibility criteria of people that can participate.

In addition to the 12-minute long video informed consent, we're providing a bulleted brief document in English in case they want to keep that.

And working with the IRB, this takes a while, because it did not have a study translate documentation into American Sign Language before and so we've been working very tirelessly with our interpreters as well as our partners over in the IRB office to make sure all this is going seamlessly and we are adequately protecting our potential Deaf participants.

So as I've alluded to a few times during the presentation, we have not yet started the survey dissemination process. I'm also a full-time student and so I'm not working on this project full-time. Whenever I'm done with class work, then I am working on it full-time. But this summer, we are hoping we will start disseminating it pretty soon and we will disseminate the survey through a collaborative sampling, so that means I will send it out to people who will then be asked to send it out to people and so on, so we get this large branch of individuals.

And so we're going to be sending it out through our Community Advisory Work Group, as well as community members that I know personally, as in addition to our community-based organizations that we've partnered with.

We actually have a list of all of the community-based organizations shown on that map and we are going to be inviting all of them even if we haven't had in-depth conversations with them, we will invite all of them to share our survey and communicate with us if they would like more information.

We have partnered with the Florida Association of the Deaf where we will be sending out the survey information on their e-mail LISTSERV which is over 2,000 individuals. And we're also going to be sharing it on social media platforms in groups that Deaf individuals use most often.

So now lessons learned, our current status, and our future directions.
[Pause].

>> TYLER JAMES: So, our current status is we're soon resubmitting to the IRB to revise our recruitment materials. We've recently purchased a website and gotten a domain

name so that we could tell people the domain they can pull up on the computer. It's fideafhealth.org.

And as I mentioned a few slides ago, we do hope to launch the survey in early June and it will be open for three months; so if we launch it in early June, then it will be closed by early September or late August. And in total, we hope to be able to recruit at least 150 Deaf individuals, but optimally up to 300 Deaf individuals in that time period.
[Pause].

>> TYLER JAMES: And so after we collect all that data, we're going to, of course, analyze the data working with our Community Advisory Work Group. And the first part we want to definitely look at is determine factors associated with health literacy. We want to compare the health literacy scores that we get in the Florida Deaf community and those connected in Michigan and the Rochester samples.

We have hypothesized the Florida Deaf community will have a lower literacy and that's based on the lack of access that the Florida Deaf community is given.

In addition, we want to identify the greatest perceived health concerns of individuals in the community using that greatest health concern item and see how that matches up with the rest of the quantitative measures of the actual need to see how closely that gap is between perceived and actual.

And then of course we will work with community leaders at multiple Deaf organizations to help define health priorities for the Florida Deaf community which can be used for future applications, hopefully.

I do want to also share some lessons learned.
[Pause].

>> TYLER JAMES: Going into this project, we felt the lack of financial resources might really prohibit us from taking a community engagement research approach to this study. What we've learned is that lack of financial resources is not a good reason to not engage in communities in research; we should be trying to engage communities no matter what.

We did try to expand the size of our Deaf Community Advisory Work Group by adding a current Florida Association of the Deaf Board, as well as the Florida Deaf Black Advocates Board, but they were fine with us just sending updates on the current study. So at the same time that we send Deaf Community Advisory Work Group members updates, we also send it to other community-based organizations.

We really found that engaging the community enhances this research project into something more than just the research team's project. We're hoping to be able to find things that can be used by the community, which is ultimately more meaningful than the research that's just being published.

And of note, this practice can be applied to other communities, so any community that falls within the broader disability community or any geographic location, racial and ethnic communities, this process of community engagement and gaining cultural insight

whenever we're developing measurement tools can be used for any community.

So I do want to provide a little bit of thanks, I should say a lot of thanks, to the Florida Deaf community and the Florida Association of the Deaf. FAD has been supportive of this effort since its inception last May.

I would also like to thank the Florida Disability and Health Program and the staff at the Florida Department of Health for inviting me to speak on today's webinar and getting an ASL interpreter for this webinar, and also for providing assistance throughout the conception of the project. The principal investigator of the Florida Disability and Health Program actually wrote us a letter of support for that grant application and we're very thankful for that.

I would also like to thank Ashleigh T. Poole, a soon-to-be graduate from University of Florida, in creating the GIS map.

And lastly, I would like to thank all of you for attending.

If there are any questions, I would be happy to answer them.

>> Nobody has put any questions into the question box yet. I have one: Is tobacco use included on the health behavior survey?

>> TYLER JAMES: Yes, ma'am, we are including tobacco use. Interestingly, in the Rochester Deaf samples, we're actually seeing that hearing individuals whenever adjusting for other socioeconomic factors, hearing individuals are using alcohol -- excuse me, tobacco more, where the Deaf community is using it less. And we're not sure what we're going to find here in Florida, but we did make sure to include the tobacco use item.

>> Great. Is it just combustible cigarettes or did you include e-cigarettes?

>> TYLER JAMES: Absolutely, so we were initially going to use the e-cigarette in addition to a combustible cigarette, but based on the length of the survey, we had to really cut down on questions, so we only cut the combustible cigarettes, so it's in the last 30 days, have you smoked a cigarette.

>> Okay. That's good.

>> TYLER JAMES: Thank you for that question.

>> Okay. Go ahead.

>> MEAGAN SULLIVAN: Okay. This is Meagan speaking. Wonderful. Thank you so much, Tyler.

Marion, you mentioned there was no questions in the chat box; did any pop up while you were speaking?

>> Not yet. Oh, wait, here's one: Will a recording of the presentation be available?

>> MEAGAN SULLIVAN: Yes. So we are recording our presentation and we will be sending it out to our Disability Planning Group.

[Pause].

>> TYLER JAMES: And this is Tyler speaking. If anyone has any questions for me that pop up later, my e-mail is listed on the slide, it is tjames95@ufl.edu and in addition the Disability and Health Program staff have my contact information.

>> Great. And also you got a "great presentation" comment, which I second.

>> TYLER JAMES: [Laughs]. Thank you all.

>> MEAGAN SULLIVAN: Okay. Seeing as we've been through the questions, we're very thankful for everyone for joining us today and Tyler for presenting. And we hope that everyone has a wonderful week. And we're going to go ahead and close out the presentation.

[End of webinar].

** Edited**